

Glossary

Term	Definition
Clinical terminology standards	Standard sets of terms, names and codes to be used when entering data in electronic records. For example, SNOMED-CT (Systemised Nomenclature of Medicine – Clinical Terms) provides a broad set of standardised clinical terms for software applications.
Confidentiality	Confidentiality relates to disclosure or nondisclosure of information. Historically a duty to honour confidentiality has arisen with respect to information disclosed in the context of a confidential relationship, such as that between an individual and his or her physician, attorney, or priest. In such relationships, the confidante is under an obligation not to disclose the information learned in the course of the relationship. Now the law applies such duties to some holders of information who do not have a confidential relationship to a patient. The importance of confidentiality to the medical profession is reflected in the physician's "Oath of Hippocrates".
Controlled vocabulary	Controlled vocabulary requires data to be input using predefined, authorised terms that have been preselected by the designer of the vocabulary.
Data confidentiality	Data confidentiality is a property of data, usually resulting from legislative measures, which prevents it from unauthorised disclosure.
Data protection	Data protection refers to the set of privacy-motivated laws, policies and procedures that aim to minimise intrusion into respondents' privacy caused by the collection, storage and dissemination of personal data.
Database record	A database record is a row of data in a database table consisting of a single value from each column of data in the table. The data in the columns in a table are all of the same type of data, such as birth date or address, whereas the rows represent a given instance, such as a single patient or person or a group of patients or persons.
De-identified information	This is information which does not identify an individual directly, and which cannot reasonably be used to determine identity. De-identification, also referred to as anonymisation, requires the removal of name and exact address; and can also involve the removal of any other detail or combination of details that might support identification.
Deterministic record linkage	In this approach, often referred to as exact matching, a unique identifier or set of identifiers is used to merge two or more sources of data. In health linkages, the identifier used is often a unique patient identifying number or UPI.
Electronic health record	For this OECD study, an electronic health record (EHR) refers to the longitudinal electronic record of an individual patient that contains or virtually links records together from multiple Electronic Medical Records (EMRs) which can then be shared across health care settings (interoperable). It aims to contain a history of contact with the health care system for individual patients from multiple organisations that deliver care.
Electronic medical record/Electronic patient record	For this OECD study, an electronic medical record (EMR) or electronic patient record (EPR) is a computerised medical record created in an organisation that delivers care, such as a hospital or physician's office, for patients of that organisation. EMR/EPR is provider or organisation centric and allows storage, retrieval and modification of patient records.
Formal long-term care	Long-term care is the care for people needing support in many facets of living over a prolonged period of time. Formal long-term care can be provided in home, institutional or day-care settings, from public, not-for-profit and for-profit providers, with services varying from alarm systems to daily personal care.
Health data	Health data usually consists of individual, personal health and other related information. The European Group on Ethics in Science and New Technologies (EGE), in the Opinion No. 13 Ethical Issues of Health Care in Information Society ¹ defines "health data" as including "a wide range of information about an individual, which all touch upon an individual's private life". A health biography could include not only basic medical data: a history of all medical diagnoses, diseases and medical interventions, medications prescribed, test results, including imaging, etc. but could also include more sensitive data: on mental health, relevant to family history, behavioural patterns, sexual life, social and economic factors, etc. and health care administrative data: admissions and discharge data routine operational data, insurance and financial transactional data, etc.

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Identifiable data	Data is identifiable if the information contains the name of an individual, or other identifying items such as birth date, address or geocoding. Data will be identifiable if the information contains a unique personal identifier and the holder of the information also has the master list linking the identifiers to individuals. Data may also be identifiable because of the number of different pieces of information known about a particular individual. It may also be possible to ascertain the identity of individuals from aggregated data where there are very few individuals in a particular category. Identifiability is dependent on the amount of information held and also on the skills and technology of the holder.
Interoperability	Interoperability is the ability of two or more systems to exchange information and to make use of exchanged information. It is an essential pre-condition to the development of electronic health records from the electronic medical records within multiple health care organisations.
Messaging standards	Messaging standards facilitate interoperability by defining how information will be communicated from one party to another. For example, Health Level 7 is a messaging standard for the exchange of clinical, financial and administrative data.
Network of health care organisations	A network of health care organisations provides a continuum of health care services. The network may provide integrated care under a parent holding company. Some networks have a Health Maintenance Organisation (HMO) component.
Population census	A population census is the total process of collecting, compiling, evaluating, analysing and publishing or otherwise disseminating demographic, economic and social data pertaining, at a specified time, to all persons in a country or in a well delimited part of a country.
Privacy	Privacy is not being observed or disturbed by others. Privacy is a concept that applies to data subjects, while confidentiality is a concept that applies to data.
Probabilistic record linkage	In this approach, a set of possible matches among the data sources to be linked are identified. For example, identifying information such as names, dates of birth, and postal codes, may be used to assess potential matches. Then statistics are calculated to assign weights describing the likelihood the records match. A combined score represents the probability that the records refer to the same entity. Often there is one threshold above which a pair is considered a match, and another threshold below which it is considered not to be a match. This technique is used when an exact match between records across databases is not possible, or when data capture errors have caused deterministic matches to fail.
Record linkage	Record linkage refers to a merging that brings together identifiable records from two or more sources of data with the object of consolidating facts concerning an individual or an event that are not available in any separate record. ²
Structured data elements	Structured data elements are identifiable. The most common type of structured data is fields in a database. For example, when a field in a database contains dates where each date has the same structure, i.e. MM/DD/YY; a computer process can easily sort the data.
Unstructured data elements	Unstructured data elements have no identifiable structure. In health records, the most common example is free flowing text.

1. European Commission (2009), "European Group on Ethics in Science and New Technologies Option No. 13", Ethical Issues of Healthcare in the Information Society, www.ec.europa.eu/bepa/european-group-ethics/docs/avis13_en.pdf.

2. United Nations (1991), *Handbook of Vital Statistics Systems and Methods*, Vol. 1: Legal, Organizational and Technical Aspects, United Nations Studies in Methods, Glossary, Series F, No. 35, New York.



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